



# The Beacon

## The Newsletter of the Wisconsin Deafblind Technical Assistance Project

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### WDBTAP Family Gains Knowledge and Support with Series of Conferences

By Wendy Koser

Once upon a time, I was a regular mom with a regular life. Or, was that a dream? Life in the Koser house has been topsy-turvy for 2-1/2 years. It's difficult to remember life without medical appointments, therapy sessions, with all of the people coming and going in our home, driving to Madison every other day, and so on.

I would like to tell you a little bit about our family. My husband Jon and I have two grown boys, David (29) and Christopher (26), and three daughters, Azia Lynn (12), Kianna (4) and our youngest, Lillee. Lillee is a two-and-a-half year-old and she is such a sweet, sweet girl. By looking at her, you wouldn't know that she has multiple medical conditions.

Lillee was diagnosed with CHARGE Syndrome. To most people she probably doesn't look like a "CHARGE". Her facial features are quite ordinary. Her speech and mobility are quite good, thanks to early intervention. She has bilateral sensorineural hearing loss, which is currently on the mild side. She wears hearing aids at home. She has underdeveloped cochlea bilaterally, along with balance and coordination problems. She has a coloboma in her right eye, affecting her vision.

Her major medical problem is Stage 3 kidney disease (lab percentages are terrifyingly close to Stage 4) and a single low functioning kidney, working at 35%. It wasn't until recently that I was made aware that she is actually deafblind, even though she can see and hear. These are not her only medical problems but it summarizes her major ones.

I have been handling Lillee's medical issues and appointments nonstop since she was 4 weeks

old. I have been told, "You're lucky that's all she has!" As far as CHARGE goes, every child has unique medical circumstances. Lillee does not have a heart condition, trach tube or facial palsy, but she does have chronic UTIs. Anytime her temperature grazes 99.0, we head straight to the pediatrician or urgent care to get a urinary catheterization. I worry for the day that her creatinine labs are "just too high" to adjust medication any further and they say the word "transplant." Those are my CHARGE realities, and I felt like I was drowning in a sea of "the unknown!" Finally, this year, I have been trying to educate myself and my family further in the different major medical areas of concern that will be with Lillee lifelong.



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After one of Lillee's genetics appointments, I was put in contact with Dr. Donna Martin of the University of Michigan to become part of a research project she was heading. She, herself, actually contacted me on the phone. She told me about the CHARGE organization and the conference that was going to happen only 4 short weeks away.

I was able to go to the CHARGE Conference in Schaumburg, IL in July. This was a family conference but I went by myself. I am so thankful I went. I gained so much knowledge and met other families with kids who have CHARGE Syndrome. It was all so wonderful. If I could have cloned myself to go to each and every breakout session available I would have. I was there to soak up all of the information that I could. I was able to participate in a research project with Dr. Kasee Stratton from Mississippi State University. I had the pleasure of meeting her and Dr Martin as well. While attending a session with Meg Hefner, I realized that I needed to pursue further ophthalmological inquiries. Additionally, I met 2 families from the Janesville area who I hadn't known previously. That connection was awesome! It was simply a mind-blowing conference, to say the least.

Shortly after I committed myself to going to the CHARGE conference, I was made aware that there was a conference for Attachment disorders in Minnesota in September. Lillee's sister, Kianna, has RAD. Reactive Attachment Disorder is a very complicated behavioral disorder. Traditional parenting techniques do not work with children with this diagnosis, making the job of being a mom all the more difficult. RAD parents are often given well-meaning but unhelpful advice by family and friends; such as, "use a reward," "she just needs to run around a little more," "you need to be more strict," and so on. Attending this



***"Knowledge can only make us stronger and greater advocates for both Lillee and Kianna no matter what circumstances we face in the future." ~ Wendy Koser***

conference was very important to me because Kianna's mental health is equally as important as Lillee's medical health. Again I was able to attend incredible sessions, make some great connections and come home with a better mindset.

Shortly after returning from the Attachment conference, I found myself registering for yet another conference. This was the WESP-DHH/WDBTAP Family Conference held in Pewaukee in October. The keynote speaker for this conference was a mom of a son with CHARGE syndrome. At the time I was thinking there is no way we can go, a 3rd conference...that is just crazy!! However, Lillee is so young and I see our need as a family to become educated now and going forward rather than back pedaling once her hearing, vision or anything else changes. Knowledge can only make us stronger and greater advocates for both Lillee and Kianna no matter what circumstances we face in the future. So, off we went and it was great!!

Within 5 minutes of being there Lillee saw two people she already knew; Christi Hess, from Birth to Three and Heidi Hollenberger, from the Wisconsin Deafblind Technical Assistance Project. She was definitely at home!!

Friday evening Jon and I visited all of the vendor tables, which are always filled with wonderful goodies for the kids. We got some great resource material and were able to talk with a representative from the Wisconsin School for the Deaf in Delavan. One of the tables had a Braille machine, so my daughter Azia Lynn and I both punched our names out in Braille. It was quite fascinating, to say the least! ~ **Wendy Koser**

# A Visit to Our Lending Library

To request these or any materials please visit [www.wdbtap.wi.gov/library](http://www.wdbtap.wi.gov/library)

## Mini-Shooting Stars!

Press the clear plastic cover and make stars shoot all around while the device lights up, plays music and vibrates. Enhances visual attention and sensory awareness. Batteries included.



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## Touchable Counting Books - Set of Three

Three books featuring ladybugs, silly monkeys, and glow-in-the-dark stars make counting down from five a cute, tactile experience



## Anderson Notes

From WDBTAP Family Specialist  
Jodi Anderson  
(Jodi is also an active member of NCDB)



## Online Parent/Family Training: The Role of Interveners in Educational Settings

NFADB (National Family Association for Deaf-Blind) and NCDB have teamed up to offer training that provides an introduction to the role of interveners in educational settings. The training uses Module 3 from the *Open Hands Open Access Intervener Learning Modules*. Patti McGowan (NFADB) and Peggy Malloy (NCDB) have been hosting these trainings online for free to families. If you are interested in joining the next group, please contact either one of them: Peggy Malloy ([malloyp@mail.wou.edu](mailto:malloyp@mail.wou.edu)) or Patti McGowan ([pmcgowan@pattan.net](mailto:pmcgowan@pattan.net)). They would love to have you and I know you will enjoy meeting other families in our network.



## For Families ([nationaldb.org/families](http://nationaldb.org/families))

We want your stories told, so the "For Families" section of the NCDB website is in the process of getting a facelift. Family stories with links to relevant resources and tips, will be on this page. If you are interested in telling your story, please let me know. I hope that over time we can have at least one story from each state and show how incredibly diverse this population of learners truly is, and allow you to be inspired by other families through their triumphs and challenges.

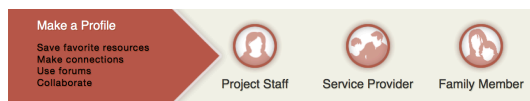


## Create a Profile on the National Center on Deaf-Blindness Website: [nationaldb.org](http://nationaldb.org)



NCDB wants you to join our national initiatives! As parents, you are the key voice in everything we do. We have set up the site so that you can create a profile and then join groups that interest you. Right now the **Family Engagement Group** has 117 members. Since there are over 10,000 learners (birth through 21) in our nation who experience deaf-blindness, I need more family voices to come learn and share with me. It may seem scary to join, but I promise you will not blow up the website. I also want to make sure you know about all of the cool things happening nationally.

Here's how you join ...



**Step 1:** Go to [nationaldb.org](http://nationaldb.org)

**Step 2:** Click on "Make a Profile" in the upper right-hand corner of the screen

**Step 3:** Fill in the information requested and click on "Create My Profile"

**You're in! Now you can join the Family Engagement Group!**

**Step 4:** From any screen on the website click on the "Connections" tab (it's in the bar across the top of the page) and choose "TA Initiative Groups"

**Step 5:** Click on the "Family Engagement" link

**Step 6:** In the upper left-hand corner of the screen click on "Join Group"

Now you are a member of the Family Engagement Group and can post to the forum. Remember that although you have to be a member to post, this is a public group and posts can be read by anyone, so take care not to post personal details.

The next time you come to the website, it is less complicated and you don't have to go through the 6-step process. Instead, just follow these steps:

**Step 1:** Login (in the upper right-hand corner of the screen) using the username and password you chose when setting up your profile.

**Step 2:** You will then see your name (also in the screen's upper-right corner). Click on the "down" arrow next to your name. The names of any groups you belong to will appear.

**Step 3:** Click on Family Engagement to go directly to the group.

I'm looking forward to hearing from you! ~

*Jodi*



The National Family Association  
for Deaf-Blind

## 2016 NFADB Symposium

[The National Family Association for Deaf-Blind \(NFADB\) Symposium Conference](#) will be held July 15-18, 2016 in Austin, TX. Registration information for the conference, ***Mobilizing A National Family Leadership Network: Improving Outcomes in Education and Services for Individuals Who Are Deaf-Blind***, will be announced soon. NFADB is a nonprofit 501c3 organization that has served families of individuals who are deaf-blind since 1994. NFADB exists to empower the voices of families of individuals who are deaf-blind and advocate for their unique needs. Visit the NFADB website at [www.nfadb.org](http://www.nfadb.org).

# In Memoriam

## By Karla Schroeder

Jacob David Schroeder of Onalaska ran into the arms of Jesus and his daddy on November 20, 2015. Jacob lived an incredible 13 years, 3 months, and 13 days full of joy and love. Our family spent many years at Lions Camp and attending DeafBlind

conferences. Jacob's dad Dave went missing 9/22/12 from our home and has not been found. Our son Michael is married with two children. Devin is a junior in high school. I am currently in the process of figuring out what to do now after being Jacob's mama and advocate for so long.

Jacob was known for his curly hair, beautiful smile, and incredible spirit which defied all odds. He was born with spina bifida and hydrocephalus and severe brain damage, which caused Jacob to be cortically visually impaired and DeafBlind. These did not define Jacob whatsoever. Yes, he was a very complex child to care for and had numerous complications in the past couple years,

but even then, Jacob never let things get him down. He joked with the doctors and nurses, he thought he owned Mayo Clinic, he admired his fan club, and boy, did he SHINE!

Jacob loved school. He was constantly the center of attention, not because he demanded it, but because people were always drawn to him. He loved his life.



He had a mission to make the world a happier place and to touch people at the very core of their being.

Jacob has been declared a medical miracle as his brain was seriously damaged, yet through doing so many of the things we learned through Wisconsin DeafBlind conferences, he grew brain tissue and had intact areas of his brain which Mayo researchers cannot understand.

This is a testimony of a parent's love, an attitude that Jacob was so worth it, and continuing to expose and encourage him all the time because we never knew just what he may be learning. Keys were repetition, repetition, repetition, LOTS of music, talking to and explaining to him things we were doing, and to never, EVER give up!

I want to send a big thank you to all staff who encouraged me to look at Jacob differently, for all the ideas on how to help Jacob learn, to see life through his eyes and ears, and to have a lot of fun doing it! You gave me the encouragement to be a better parent. You gave me the encouragement to keep on going and knowing what I was doing mattered. You helped the staff at school and his vision teachers understand him better. Thank you so much!

My final encouragement as I look back on Jacob's life is to encourage you that the only thing that truly matters is that we LOVE our children for who they are, despite their limitations. It is in this simpleness that we are given the most intense gift ever.....the chance to love our child for who they

truly are, an amazing, amazing gift you wouldn't trade for anything, even on the hardest of days. Much love to all of you and please hug your kids for me. Each day is such a gift.

~ **Karla Schroeder**



## What Types of Technical Assistance does WDBTAP provide?

- Parent/Family trainings and assistance in connecting families with one another
- Statewide and regional workshops for service providers and families
- Observation, support and coaching in programming for children
- Intensive deafblind training series for paraprofessionals who work one on one with children and youth who are deafblind
- Assistance in identifying children and youth who are deafblind
- Referral to relevant local, regional and national agencies
- Lending library with materials, equipment and toys to benefit deafblind children/youth on the Registry

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